Factors affecting use of unscheduled care for people with advanced cancer

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Factors affecting use of unscheduled care for people with advanced cancer:

a retrospective cohort study in Scotland

Abstract

Background

People with advanced cancer frequently attend unscheduled care, but little is known about the factors influencing presentations. Most research focuses on accident and emergency (A&E) and does not consider GP out-of-hours (GPOOH).

Aim

To describe the frequency and patterns of unscheduled care use by people with cancer in their last year of life and to examine the associations of demographic and clinical factors with unscheduled care attendance.

Design and setting

Retrospective cohort study of all 2443 people who died from cancer in Tayside, Scotland, during 2012–2015. Clinical population datasets were linked to routinely collected clinical data using the Community Health Index (CHI) number.

Method

Anonymised CHI-linked data were analysed in SafeHaven, with descriptive analysis, using binary logistic regression for adjusted associations.

Results

Of the people who died from cancer, 77.9% (*n* = 1904) attended unscheduled care in the year before death. Among unscheduled care users, most only attended GPOOH (*n* = 1070, 56.2%), with the rest attending A&E only (*n* = 204, 10.7%), or both (*n* = 630, 33.1%). Many attendances occurred in the last week (*n* =1360, 19.7%), last 4 weeks (*n* = 2541, 36.7%), and last 12 weeks (*n* = 4174, 60.3%) of life. Age, sex, deprivation, and cancer type were not significantly associated with unscheduled care attendance. People living in rural areas were less likely to attend unscheduled care: adjusted odds ratio (aOR) 0.64 (95% confidence interval = 0.50 to 0.82). Pain was the commonest coded clinical reason for presenting (GPOOH: *n* = 482, 10.5%; A&E: *n* = 336, 28.8%). Of people dying from cancer, *n* = 514, 21.0%, were frequent users (≥5 attendances/year), and accounted for over half (*n* = 3986, 57.7%) of unscheduled care attendances.

Conclusion

Unscheduled care attendance by people with advanced cancer was substantially higher than previously reported, increased dramatically towards the end of life, was largely independent of demographic factors and cancer type, and was commonly for pain and palliative care.

Keywords

after-hours care; emergency service; lung cancer; pain; terminal care.

INTRODUCTION

Cancer mortality is increasing, and anticipated to reach 14.6 million annual deaths worldwide by 2040.[1] People with advanced cancer frequently experience unpleasant disease-related and treatment-related symptoms.[2–4] The onset of acute, severe, or distressing symptoms outside of normal working hours may precipitate attendance with unscheduled care services.[3] 'Unscheduled care' includes any medical service that can be accessed by the general public without prior arrangement.[5] In the UK, the majority of unscheduled care is delivered via the general practice out-of-hours (GPOOH) service or via hospital accident and emergency (A&E) departments. Unscheduled care is among the most pressurised sections of the NHS, and use of unscheduled care is increasing,[6] particularly among people with advanced cancer.[3,7–9] Much of the need for accessing unscheduled care by people with cancer is due to predictable situations, and is, therefore, potentially avoidable with good anticipatory care.[3,7,10] Although unscheduled care remains an important part of comprehensive community care for people with advanced cancer, frequent use of unscheduled care has been suggested to be a marker for poor patient care.[7,10,11] It is increasingly important to optimise use of unscheduled care by people with cancer because of its impact on quality, manner, and location of end-of-life care.[8]

Relatively little is known about the frequency and patterns with which people with advanced cancer use unscheduled care. Most research focuses on A&E and does not consider GPOOH services. This study aims to describe the frequency and patterns of any NHS unscheduled care use, by people with cancer in their last year of life, and to examine the associations of demographic and clinical factors with unscheduled care attendance.

METHOD

The overall design of this study is a retrospective cohort study of all 2443 residents of the Tayside region of Scotland (total population approximately 410 000)[12] who died from cancer over a 30-month period from 2012 to 2015. The population was identified posthumously using General Register Office death registration data, and included all those whose cause of death was cancer in position 1 of the death certificate. Routinely collected clinical data for all attendances in the last year of life were linked using the Community Health Index (CHI) number, which is used as a single patient identifier throughout NHS Scotland. CHI-linked data were obtained from the Cancer Registry (Scottish Morbidity Records),[13] Scottish Government Executive

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How this fits in

Unscheduled care use is common in people with advanced cancer, but previous research has focused largely on accident and emergency (A&E) attendances only; this has led to an underestimation of the frequency of unscheduled care use as use of general practice out-of-hours (GPOOH) services is significantly more common than A&E use. This study demonstrates that the percentage of people with cancer who use unscheduled care is significantly higher than previously shown, that demographic factors have relatively little influence on unscheduled care use, that unscheduled care attendance was linked to clinical factors including pain and palliative care symptoms, and that people who are 'frequent users' were a small proportion of the cohort but accounted for over half of unscheduled care consultations. This concentration of unscheduled care use at the end of life and among a small number of users implies that any unscheduled care use should trigger in-hours care review and anticipatory care planning. Identifying factors that affect unscheduled care use will enable clinicians to identify people at high risk of (frequent) unscheduled care use and appropriately target resources and interventions to these individuals in order to optimise care and minimise avoidable unscheduled care use.

Urban Rural Classification (SEURC, which classifies postcodes in terms of remoteness and rurality),[14] and Scottish Index of Multiple Deprivation (SIMD, categorises deprivation into quintiles from SIMD1 [most deprived] to SIMD5 [least deprived]).[15] Data were cleaned, anonymised, stored, and analysed in the SafeHaven platform (a secure virtual platform for NHS electronic data, where datasets are stored and analysed, and exported results and data meet strict research governance criteria) in the Health Informatics Centre (HIC) at the University of Dundee. Coding of clinical attendances was carried out by clinicians at the time of attendance, and recorded in the medical notes. Frequent users were defined as those with ≥5 attendances per year; very frequent users were defined as those with ≥10 attendances per year.

Analysis was descriptive, examining differences between unscheduled care users and non-users, and between users of one or other service (GPOOH or A&E), versus both, using χ^2 tests for categorical variables. Binary logistic regression was used to examine associations between any unscheduled care use, GPOOH use, and A&E use, and a range of demographical and clinical factors. Univariate and adjusted odds ratios (aOR) with their 95% confidence intervals (CIs) were calculated for each outcome using SPSS (version 25).

RESULTS

Population characteristics

In the population of 2443 people dying from cancer in the study period, the majority were males (*n* = 1278, 52.3%), most lived in urban areas (*n* = 1588, 65.3%), and the sample was evenly spread across the quintiles of deprivation. Lung cancer was the commonest cause of death (*n* = 672, 27.5%), with other common cancers including upper gastrointestinal (GI) malignancy (*n* = 514, 21.0%) and bowel cancer (*n* = 303, 12.4%), (Table 1). There was sizeable variation in the interval of diagnosis before death, with one-third of people (*n* = 831, 34.0%) being diagnosed <12 weeks before death, one-third (*n* = 877, 35.9%) diagnosed 12–51 weeks before death, and one-third (*n* = 735, 30.1%) diagnosed ≥52 weeks before death.

Patterns of use of unscheduled care

The majority (*n* = 1904, 77.9%) of people who died from cancer attended unscheduled care in their last year of life (Table 2). Many people attended only GPOOH (*n* = 1070, 43.8%); however, a substantial proportion attended both GPOOH and A&E (*n* = 630, 25.8%), and a minority attended A&E only (*n* = 204, 8.4%%). The cohort of participants had 6914 contacts with unscheduled care in their year before death; the majority of these were with GPOOH (*n* = 5749, 83.2%) with only a small amount in A&E (*n* = 1165, 16.8%) (Figure 1). The number of attendances per patient in the last year of life ranged from 0 to 61 (Table 2). Among those attending, the range in total number of attendances was larger at GPOOH (1–60 attendances/year) than at A&E (1–11 attendances/year). All frequent users (*n* = 406, 16.6% of cohort) and very frequent users (*n* = 108, 4.4% of cohort) attended GPOOH, and most attended both GPOOH and A&E. There were no frequent or very frequent users who attended only A&E.

Attendance at unscheduled care was more frequent closer to the date of death, (Figure 1). Contacts with unscheduled care became more frequent during the terminal phase of illness; a substantial proportion of attendances with unscheduled care occurred in the participants' last week (*n* = 1360, 19.7%), last 4 weeks (*n* = 2541, 36.8%), and last 12 weeks (*n* = 4174, 60.4%)

Table 1. Patient-level factors related to unscheduled care use

Factor	All patients (*N* = 2443), *n* (%)	Non-users *N* = 539 (22.1% of all patients), *n* (%)	Users *N* = 1904 (77.9% of all patients), *n* (%)	*P*-value (users versus non-users)	GPOOH only users *N* = 1070 (43.8% of all patients), *n* (%)	A&E only users *N* = 204 (8.4% of all patients), *n* (%)	Users of both *N* = 630 (25.8% of all patients), *n* (%)	*P*-value (GPOOH versus A&E versus users of both)
Age, years								
<65	478 (19.6)	114 (21.2)	364 (19.1)	0.12	214 (20.0)	35 (17.2)	115 (18.3)	0.27
65–74	662 (27.1)	160 (29.7)	502 (26.4)		263 (24.6)	58 (28.4)	181 (28.7)	
75–84	809 (33.1)	172 (31.9)	637 (33.5)		359 (33.6)	72 (35.3)	206 (32.7)	
≥85	494 (20.2)	93 (17.3)	401 (21.1)		234 (21.9)	39 (19.1)	128 (20.3)	
Sex								
Female	1165 (47.7)	247 (45.8)	918 (48.2)	0.33	536 (46.0)	81 (7.0)	301 (25.8)	0.04
Male	1278 (52.3)	292 (54.2)	986 (51.8)		534 (41.8)	123 (9.6)	329 (25.7)	
Remoteness[a]								
Urban	1588 (65.9)	320[b] (60.4)	1268 (67.4)	<0.001	696[c] (66.0)	144[d] (71.3)	428[e] (68.6)	<0.001
Accessible	587 (24.4)	166[b] (31.3)	421 (22.4)		242[c] (22.9)	48[d] (23.8)	131[e] (21.0)	
Remote	235 (9.8)	44[b] (8.3)	191 (10.2)		116[c] (11.0)	10[d] (5.0)	65[e] (10.4)	
Deprivation[a]								
SIMD1 (deprived)	422 (17.3)	97[b] (18.3)	372 (19.5)	0.04	183[c] (17.4)	53[d] (26.2)	136[e] (21.8)	0.03
SIMD2	392 (16.0)	98[b] (18.5)	430 (22.6)		244[c] (23.1)	46[d] (22.8)	140[e] (22.4)	
SIMD3	444 (18.2)	118[b] (22.3)	329 (17.3)		187[c] (17.7)	34[d] (16.8)	108[e] (17.3)	
SIMD4	731 (29.9)	103[b] (19.4)	392 (20.6)		232[c] (22.0)	30[d] (14.9)	130[e] (20.8)	
SIMD5 (affluent)	421 (17.2)	114[b] (21.5)	357 (18.8)		208[c] (19.7)	39[d] (19.3)	110[e] (17.6)	
Cancer type								
Lung	672 (27.5)	143 (21.3)	529 (78.7)	0.06	266 (39.6)	67 (10.0)	196 (29.2)	0.002
Upper GI	514 (21.0)	129 (25.1)	385 (74.9)		231 (44.9)	38 (7.4)	116 (22.6)	
Bowel	303 (12.4)	59 (19.5)	244 (80.5)		158 (52.1)	17 (5.6)	69 (22.8)	
Breast and ovarian	237 (9.7)	56 (23.6)	181 (76.4)		114 (48.1)	14 (5.9)	53 (22.4)	
Prostate	99 (4.1)	18 (18.2)	81 (81.8)		48 (48.5)	10 (10.1)	23 (23.2)	
Haematological	241 (9.9)	65 (27.0)	176 (73.0)		88 (36.5)	26 (10.8)	62 (25.7)	
Other	377 (15.4)	69 (18.3)	308 (81.7)		165 (43.8)	32 (8.5)	111 (29.4)	
Diagnosed in the last year of life								
Yes	1709 (70.0)	375 (21.9)	1334 (78.1)	0.827	727 (42.5)	155 (9.1)	452 (26.4)	0.09
No	734 (30.0)	164 (22.3)	570 (77.7)		343 (46.7)	49 (6.7)	178 (24.3)	

[a]Data for remoteness and deprivation missing for 33 patients. [b]The denominator for remoteness and deprivation for non-users: 530. [c]The denominator for remoteness and deprivation for GPOOH-only users: 1054. [d]The denominator for remoteness and deprivation for A&E-only users: 202. [e]The denominator for remoteness and deprivation for GPOOH and A&E users: 624. A&E = accident and emergency services. GI = gastrointestinal. GPOOH = GP out-of-hours service. SIMD = Scottish Index of Multiple Deprivation.[15]

of life. This trend was seen in both GPOOH and A&E.

Clinical reasons for unscheduled care use

Of the 5749 consultations in GPOOH, only 4587 were given a clinical Read Code. The 1162 consultations that had missing clinical codes were excluded from these percentage calculations in order to give the percentage of coded clinical contacts.

Palliative care represented the largest category of coded presenting complaints in GPOOH (Table 3), with pain, breathlessness, infection, GI symptoms, and medication requests also being common. In A&E, pain, acute neurological conditions, falls, and breathlessness were the commonest reasons for attendance. Although A&E data had no consultations with missing clinical data, a significant proportion of attendances were generically coded as 'unwell'. Regarding outcomes, very few GPOOH consultations out of all GPOOH attendances including those with missing clinical coding (*n* = 31, 0.5%) resulted in a direct referral to other clinicians, and there was no coded breakdown of what proportion were referred directly to A&E. One in 10 GPOOH attendances resulted in admission to hospital (*n* = 629, 10.9%). In this area, the majority of hospital admissions from GPOOH went directly to the medical admission unit or surgical admission unit; however, there was a possibility that more unwell patients could have been sent to hospital via A&E. One in five contacts with GPOOH were managed by district nurses, either as NHS24 phone advice (*n* = 592,

Table 2. Unscheduled care attendance numbers in the last year of life

Unscheduled care attendance	All patients (*N* = 2443), *n* (%)	GPOOH only, *n* (%)	A&E only, *n* (%)	Both GPOOH and A&E, *n* (%)
Patients using each type of unscheduled care	1904 (77.9)	1070 (43.8)	204 (8.4)	630 (25.8)
Unscheduled care attendances per person in the last year of life				
0	539 (100)[a]	—	—	—
1	487 (25.6)[b]	340 (31.8)	147 (72.1)	—
2	413 (21.7)[b]	260 (24.3)	38 (18.6)	116 (18.4)
3	281 (14.8)[b]	151 (14.2)	14 (6.9)	115 (18.3)
4	209 (11.0)[b]	95 (8.9)	5 (2.5)	109 (17.3)
5–9 (frequent users)	406 (21.3)[b]	187 (17.4)	0	219 (34.8)
≥10 (very frequent users)	108 (5.7)[b]	37 (3.5)	0	71 (11.3)

[a]Percentage of non-users. A&E = accident and emergency services. [b]Percentage of patients using unscheduled care (n = 1904). GPOOH = GP out-of-hours service.

10.3%) or as district nurse home visits (*n* = 548, 9.5%).

Demographic and clinical characteristics associated with unscheduled care use

Demographic data showed little association with unscheduled care attendance (Table 4). Age, sex, cancer type, and deprivation were not significantly associated with whether or not people attended unscheduled care. People living in rural areas were significantly less likely to use unscheduled care than their urban counterparts (aOR 0.64, 95% CI = 0.50 to 0.82). Recency of diagnosis was not significantly associated with whether or not people used unscheduled care, nor with the kind of unscheduled care that they used (Table 4).

Certain demographic factors affected A&E and GPOOH use differently (Table 5). Males were less likely to use GPOOH (adjusted OR 0.81, 95% CI = 0.67 to 0.98) than females, but sex did not significantly affect A&E use. Cancer type did not

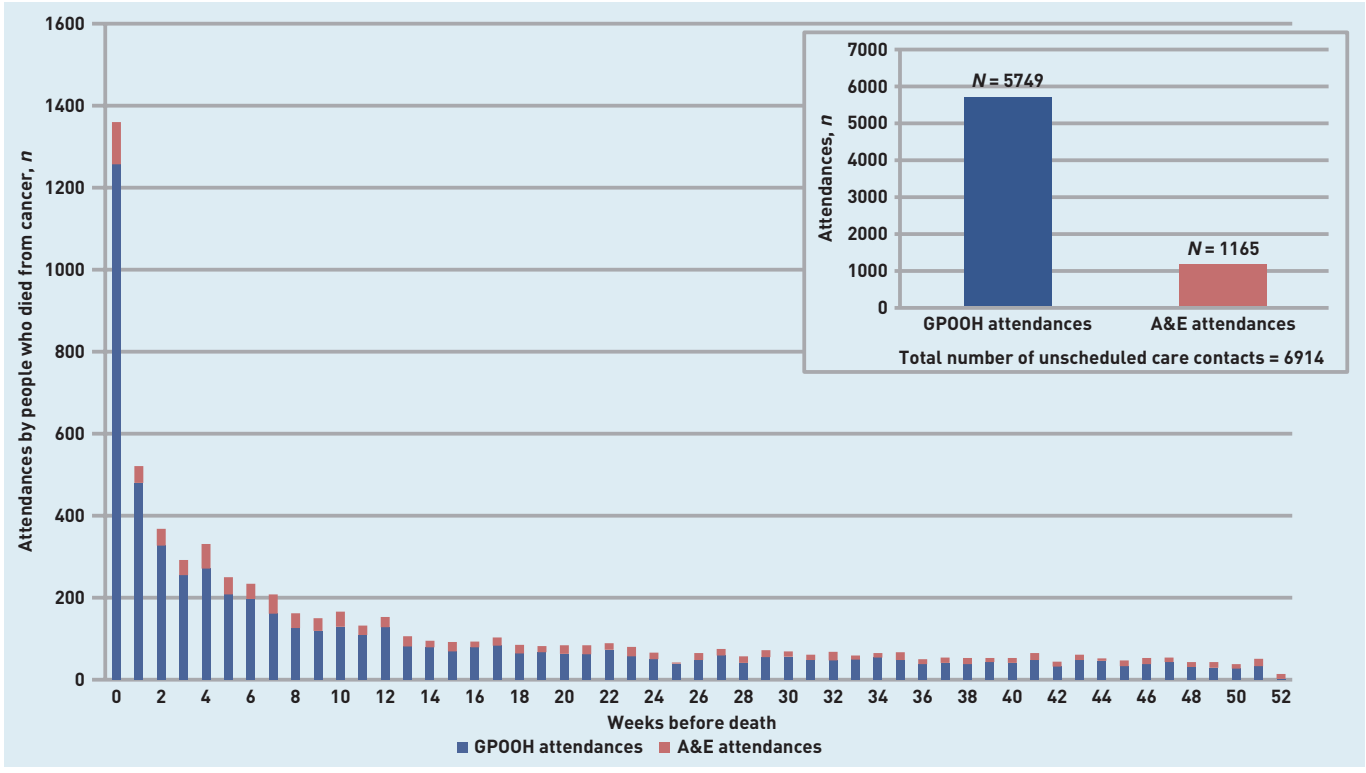

Figure 1. Unscheduled care attendances at GPOOH and A&E, in total and per week, over the last year of life. A&E = accident and emergency services. GPOOH = GP out-of-hours service.

Table 3. Unscheduled care contact reasons, attendance types, and clinical priorities

GPOOH	GPOOH (*N* = 5749 attendances), *n* (%)	A&E (*N* = 1165 attendances), *n* (%)	A&E
Coded reason for contact[a]			**Coded reason for contact**
Palliative care	1109 (24.2)[a]	216 (18.5)	Unwell
Pain	482 (10.5)[a]	336 (28.8)	Pain
Breathlessness	105 (2.3)[a]	143 (12.3)	Breathlessness
Infection	561 (12.2)[a]	30 (2.6)	Infection
GI symptom	330 (7.2)[a]	28 (2.4)	GI symptom
Acute neurological symptoms	50 (1.1)[a]	164 (14.1)	Acute neurological condition
Mental health	20 (0.4)[a]	1 (0.1)	Mental health
Medication request	257 (5.6)[a]	172 (14.8)	Fall
Other	1673 (36.5)[a]	75 (6.4)	Other
Missing	1162 (20.2)	0	Missing
Attendance type and setting for GP contact			**Mode of arrival**
Home visit	2876 (50.0)	848 (72.8)	Ambulance
NHS24 nurse advice	592 (10.3)	305 (26.2)	Private transport
District nurse visit	548 (9.5)	6 (0.5)	Public transport
In-person attendance for appointment at OOH centre	410 (7.1)	6 (0.5)	Other
See and treat	297 (5.2)	—	
Telephone advice from GP	934 (16.2)	—	
Other	92 (1.6)	—	
Clinical priority ascribed			**Clinical priority ascribed**
Emergency	342 (5.9)	227 (19.5)	Resuscitation
Urgent	1854 (32.2)	613 (52.6)	Majors
Routine	3110 (54.1)	325 (27.9)	Minors
NHS24 Advice	443 (7.7)	—	

[a]Contacts with missing clinical coding, n *= 1162, were excluded from the denominator when calculating percentage. There are 5749 total GPOOH consultations and 4587 'coded' GP OOH consultations (consultations for which there is a clinical Read Code given, which excludes the 1162 consultations that are 'missing' Read Codes/ uncoded). The percentages given use 4587 as the denominator in order to give the percentage of coded contacts. A&E = accident and emergency services. GI = gastrointestinal. GPOOH = GP out-of-hours service.*

appear to affect GPOOH attendances, but had a significant association with A&E attendances: people with lung cancer were 1.5 times more likely to attend A&E than those with upper GI and bowel cancers. This difference may be because of different cancer types influencing the nature and severity of presenting complaints, and therefore affecting the urgency of care required, and the choice between A&E and GPOOH. However, the authors are unable to confirm this with the data available, and more research is required. People from less deprived (SIMD3) and least deprived (SIMD5) backgrounds were less likely to use A&E than those from deprived (SIMD1) backgrounds; however, deprivation had no effect on GPOOH use. Although rurality had no significant impact on A&E use, people living rurally were significantly less likely to attend GPOOH (aOR 0.66, CI = 0.53 to 0.83) than those living in urban areas.

DISCUSSION

Summary

The majority of people with advanced cancer used unscheduled care in their last year of life, with attendances occurring predominantly in the last weeks of life. People who used unscheduled care were much more likely to use GPOOH than A&E. One in four people who used unscheduled care attended ≥5 times (frequent users) and one in 20 attended ≥10 (very frequent users). Attendances increased dramatically close to date of death, with 60.3% occurring in the last 12 weeks of life and 19.7% in the last 4 weeks. Rurality was the only demographic factor to be consistently associated with unscheduled care use, with people living in rural areas less likely to attend any unscheduled care. Pain, breathlessness, infections, and GI symptoms were the commonest specific coded reasons for people presenting to unscheduled care.

Table 4. Logistic regression comparing factors associated with those who attended unscheduled care in the last year of life and those who did not

Factor	*N*	Unscheduled care users *n* (%)	Univariate OR (95% CI)	Adjusted OR (95% CI)
Age, per year[a]	2443	1904 (77.9)	1.01 (1.00 to 1.02)	1.01 (1.00 to 1.02)
Sex				
Female	1165	918 (48.2)	1	1
Male	1278	986 (51.8)	0.91 (0.75 to 1.10)	0.88 (0.71 to 1.09)
Remoteness[b]				
Urban	1588	1268 (79.8)	1	1
Rural	587	421 (71.7)	0.64 (0.52 to 0.80)	0.64 (0.50 to 0.82)
Remote	235	191 (81.3)	1.10 (0.77 to 1.55)	1.09 (0.76 to 1.57)
Deprivation[b]				
SIMD1 (deprived)	469	372 (79.3)	1	1
SIMD2	528	430 (81.4)	1.47 (0.66 to 3.27)	1.17 (0.82 to 1.67)
SIMD3	447	329 (73.6)	1.70 (0.76 to 3.80)	0.90 (0.64 to 1.26)
SIMD4	495	392 (79.2)	1.17 (0.53 to 2.59)	1.05 (0.75 to 1.46)
SIMD5 (affluent)	471	357 (75.8)	1.32 (0.60 to 2.89)	0.85 (0.61 to 1.19)
Cancer type				
Lung	672	529 (78.7)	1	1
Upper GI	514	385 (74.9)	0.83 (0.60 to 1.14)	0.82 (0.62 to 1.09)
Bowel	303	244 (80.5)	0.67 (0.48 to 0.93)	1.14 (0.80 to 1.62)
Breast and ovarian	237	181 (76.4)	0.93 (0.63 to 1.36)	0.84 (0.57 to 1.23)
Prostate	99	81 (81.8)	0.72 (0.49 to 1.08)	1.32 (0.75 to 2.33)
Haematological	241	176 (73.0)	1.01 (0.57 to 1.79)	0.74 (0.52 to 1.04)
Other	377	308 (81.7)	0.61 (0.41 to 0.89)	1.27 (0.91 to 1.76)
Diagnosed in the last year of life				
Yes	1709	1334 (78.1)	1	1
No	734	570 (77.7)	1.02 (0.83 to 1.26)	0.99 (0.79 to 1.24)

[a]Age is used as a continuous variable, and the unit used was 'per year' with the odds ratio given being the change in odds per year of life. [b]Data for deprivation and remoteness missing for 33 patients. GI = gastrointestinal. OR = odds ratio. SIMD = Scottish Index of Multiple Deprivation.[15]

Strengths and limitations

To the authors' knowledge this is the first time that a cohort study has been used to examine UK unscheduled care use by people with cancer in both A&E and GPOOH. Using population data, compared with previous studies examining unscheduled care attenders, gives a more comprehensive and accurate picture of unscheduled care use.

The demographic and cancer diagnosis data were >98.5% complete; however, clinical coding of reason for attendance was more variable, with 20.2% missing in GPOOH and a similar proportion of A&E coding being non-specific ('unwell').

Comparison with existing literature

Frequency of use of unscheduled care. This study suggests that people who die from cancer use unscheduled care significantly more than has been previously reported. Current literature examining unscheduled care has suggested that approximately 30–35% of people with cancer use unscheduled care services.[3,16,17] However, these estimates[4,16–28] are often limited in terms of scope and applicability because they are not based on the population of people with cancer, but typically only examine people attending A&E whose attendance is coded as being for cancer. They therefore cannot accurately examine unscheduled care use in the whole population because they cannot observe those people who do not present to unscheduled care, or those where their presentation is not specifically coded as 'cancer' but who may be there for cancer-related reasons.

There was a wide range in the number of presentations per person to unscheduled care in the last year of life, particularly to GPOOH. Importantly, frequent users and very frequent users were 21.0% of the total cohort population, yet accounted for over half (n = 3990, 57.7%) of the cohort's 6914 attendances with unscheduled care.

Table 5. Logistic regression comparing factors associated with those who attended either GPOOH or A&E for unscheduled care in the last year of life with those who did not

Factors	*N*	GPOOH users, *n* (%)	Univariate OR (95% CI)	Adjusted OR (95% CI)	A&E users, *n* (%)	Univariate OR (95% CI)	Adjusted OR (95% CI)
Age, per year[a]	2443	1700 (69.6)	1.01 (1.00 to 1.02)	1.01 (0.99 to 1.01)	834 (34.1)	1.00 (1.00 to 1.01)	1.00 (1.00 to 1.01)
Sex							
Female	1165	837 (71.8)	1	1	382 (32.8)	1	1
Male	1278	864 (67.6)	0.81 (0.67 to 0.99)	0.81 (0.67 to 0.98)	452 (35.4)	1.09 (0.91 to 1.31)	1.10 (0.91 to 1.31)
Remoteness[b]							
Urban	1588	1125[c] (70.8)	1	1	572[d] (36.0)	1	1
Rural	587	373[c] (63.5)	0.69 (0.55 to 0.87)	0.66 (0.53 to 0.83)	179[d] (30.5)	0.84 (0.67 to 1.06)	0.83 (0.66 to 1.05)
Remote	235	181[c] (77.0)	1.31 (0.93 to 1.84)	1.29 (0.92 to 1.80)	75[d] (31.9)	0.90 (0.66 to 1.22)	0.88 (0.65 to 1.20)
Deprivation[b]							
SIMD1 (deprived)	422	287 (61.2)	1	1	173 (36.8)	1	1
SIMD2	392	283 (53.6)	1.25 (0.95 to 1.65)	1.22 (0.90 to 1.65)	141 (26.7)	0.83 (0.64 to 1.08)	0.82 (0.62 to 1.10)
SIMD3	444	303 (67.8)	1.02 (0.76 to 1.39)	1.10 (0.81 to 1.49)	141 (31.8)	0.76 (0.56 to 1.02)	0.73 (0.54 to 0.98)
SIMD4	731	521 (71.3)	1.35 (0.99 to 1.84)	1.29 (0.96 to 1.73)	242 (33.1)	0.81 (0.61 to 1.08)	0.82 (0.63 to 1.09)
SIMD5 (affluent)	421	285 (67.7)	1.00 (0.75 to 1.33)	1.02 (0.76 to 1.38)	129 (30.6)	0.74 (0.56 to 0.98)	0.69 (0.52 to 0.93)
Cancer type							
Lung	672	462 (68.8)	1	1	263 (39.1)	1	1
Upper GI	514	348 (67.7)	0.95 (0.74 to 1.22)	0.96 (0.75 to 1.24)	154 (30.0)	0.67 (0.52 to 0.86)	0.66 (0.52 to 0.85)
Bowel	303	227 (74.9)	1.28 (0.94 to 1.77)	1.31 (0.96 to 1.80)	86 (28.4)	0.65 (0.48 to 0.89)	0.65 (0.48 to 0.87)
Breast and ovarian	237	167 (70.5)	0.91 (0.64 to 1.30)	0.93 (0.66 to 1.32)	67 (28.3)	0.70 (0.49 to 0.99)	0.70 (0.49 to 0.98)
Prostate	99	71 (71.7)	1.21 (0.74 to 1.98)	1.21 (0.74 to 1.98)	33 (33.3)	0.82 (0.52 to 1.32)	0.82 (0.51 to 1.30)
Haematological	241	150 (62.2)	0.73 (0.53 to 1.00)	0.73 (0.54 to 1.00)	88 (36.5)	0.92 (0.67 to 1.25)	0.92 (0.67 to 1.25)
Other	377	276 (73.2)	1.25 (0.94 to 1.67)	1.27 (0.96 to 1.70)	143 (37.9)	0.97 (0.75 to 1.27)	0.97 (0.74 to 1.26)
Diagnosed in the last year of life							
Yes	1709	1180 (69.0)	1	1	607 (35.5)	1	1
No	734	521 (71.0)	1.10 (0.89 to 1.34)	1.09 (0.89 to 1.34)	227 (30.9)	0.99 (0.79 to 1.20)	0.84 (0.69 to 1.03)

[a]Age is used as a continuous variable, and the unit used was 'per year' with the odds ratio given being the change in odds per year of life. [b]Data for remoteness and deprivation missing for 33 patients. [c]Data for remoteness, GPOOH users, missing for 21 patients. [d]Data for remoteness, A&E users, missing for 8 patients. A&E = accident and emergency services. GI = gastrointestinal. GPOOH = GP out-of-hours service. OR = odds ratio. SIMD = Scottish Index of Multiple Deprivation.[15]

Clinical reasons for unscheduled care use. Pain was the single commonest presenting complaint in both GPOOH and A&E, representing one-third of A&E attendances, and 1 in 10 presentations to GPOOH. While still substantial, this figure may under-represent the true effect of pain, as pain is likely to have featured in a significant proportion of GPOOH attendances coded as 'palliative care' (only a single clinical code could be applied at each attendance). Breathlessness, infections, and GI symptoms were also common reasons for presenting to GPOOH or A&E. These results are consistent with the findings of other studies, which found that pain,[4,16,18–25] breathlessness,[19,21–24,26] and gastrointestinal symptoms[19,21–24,26] are the commonest reasons for unscheduled care use.

Patient characteristics and unscheduled care use. Previous studies have reported that unscheduled care use is more common in older adults with cancer,[17,18] but this study found no strong evidence of an association with age. This is possibly because previous studies only examined attenders at A&E or GPOOH, whereas this study examined a cohort of people who died from cancer, or because previous studies looked at larger, for example, 10-year effect, sizes, rather than effect per year. A possible explanation is that age is not associated with unscheduled care use in people with cancer who are dying, but is in the wider population because older people are more likely to die from their cancer. Previous studies based on people with cancer attending A&E found that more A&E attenders with cancer are males than females,[16–18,29,30] whereas this cohort study found no significant association between sex and A&E use but did determine that females are more likely than males to use GPOOH.

Past research has suggested that people with lung cancer are more likely to use unscheduled care.[16–18,21,27] These studies focus on attendance-level rather than

population-level data, and often incorrectly infer from the fact that people with cancer who attend unscheduled care are most likely to have lung cancer, that people with lung cancer are more likely to attend unscheduled care than those without other cancers. They also tend to focus solely on A&E and ignore GPOOH. Although this study did find that the plurality of attendances in GPOOH and A&E were by people with lung cancer, and that people with lung cancer were more likely to attend A&E than those with upper GI, bowel, and breast and ovarian cancers, this was not true of other cancer types. Moreover, people with lung cancer were not more likely to use GPOOH, or unscheduled care overall, than those with other cancers.

The present study demonstrates that people in rural areas use unscheduled care less than people in urban areas; previous research in this area suggests otherwise,[17] but is largely based on A&E use in non-UK populations.

Earlier studies indicate that people living in deprived areas are more likely to use unscheduled care;[18,19] this study supports this finding for A&E attendance but not for GPOOH or unscheduled care as a whole. These differences underscore the importance of not applying A&E-specific findings to unscheduled care as a whole, and on not conflating attendance-level data with population-level behaviour.

Implications for research and practice

This analysis finds that the extent of unscheduled care use by people who die from cancer is significantly greater than previously estimated, and that the majority of this care is delivered in GPOOH. This implies that unscheduled care use is a larger issue and more worthy of consideration and attention than previously thought, and that GPOOH should be at the forefront of service planning, design, and delivery for any unscheduled care interventions or policies.

There were significant variations between GPOOH use and A&E use, which underscores the importance of using GPOOH data for policies and service delivery relating to GPOOH, rather than assuming A&E data to be universally applicable to all unscheduled care. Over one-third of all unscheduled care attendances are due to pain and other palliative symptoms. Targeted interventions to improve symptom control and management could reduce unscheduled care use, minimise distress, and provide timely relief without the delays inherent in attending unscheduled care.

The clustering of unscheduled care attendances in the last weeks of life, and dramatic increase just before death, suggests that clinicians could use unscheduled care attendance as a predictor for imminence of death in people who die from cancer, and that such attendance should trigger clinicians to review patients' palliative care needs, including symptom control and anticipatory care planning. This could be useful for both providers of unscheduled care, who may feel more enabled to suggest a care review by the regular medical provider, and by the regular medical provider, who, on becoming aware of unscheduled care use, may wish to review the patients themselves.

A relatively small number of people account for over half of all unscheduled care consultations; focusing support on these people may have a significant impact on improving overall care and reduce unscheduled care use. Using unscheduled care attendance, particularly frequent attendance, as a proxy for unmet palliative care needs would allow clinicians to target support to these people in order to improve symptom control, enhance community care, and optimise information sharing between primary, secondary, and unscheduled care services.

Interventions targeted at improving anticipatory care planning, improving community support, and streamlining care pathways may help ensure that unscheduled care attendances only occur when they are appropriate and unavoidable.

This paper did not examine variation by GP practice, which could influence unscheduled care attendance, and would demonstrate the effect of in-hours care. Future research could focus on this. Also, different cancer types influence the nature and severity of presenting complaints, and therefore affect the urgency of care required, and the choice between A&E and GPOOH, but, because the authors are unable to confirm this with the data available, more research is also required on this.

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Ethical approval

The study was approved by the Tayside Research Ethics Committee (REC reference 14/ES/0015) and Caldicott Guardian (reference Caldicott/CSAppSM1952).

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Competing interests

The authors have declared no competing interests.

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